Research in Autism Spectrum Disorders 68 (2019) 101450

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

Parent focused interventions for older children or adults with ASD and parent wellbeing outcomes: A systematic review with meta-analysis

Marion Rutherford*, Anusua Singh-Roy, Robert Rush, Deborah McCartney, Anne O'Hare, Kirsty Forsyth

Queen Margaret University, University Drive, EH21 6UU, Musselburgh, United Kingdom

ARTICLE INFO

Number of reviews completed is 2

Keywords:
Autism spectrum disorder
Wellbeing
Quality of life
Parent stress
Intervention

ABSTRACT

Background: There is a need for better evidence in relation to parent-focussed interventions for older children (over 7 years) and adults, which are recommended in clinical guidelines.
Method: We conducted a systematic review of studies published between 2006 and 2016 investigating wellbeing outcomes of ASD parent focussed interventions via a search of electronic databases including MEDLINE, PsychINFO, CINAHL and the Cochrane database.
Results: We screened 9605 titles, 57 full text articles and abstracts were read. Two were systematic reviews and 22 experimental intervention studies were included for review. Of these, five were Randomised Controlled Trials, three Controlled Trials and 14 Cohort studies.
Interventions were: Parent education and training (n = 12); Mindfulness or relaxation training (n = 6), Parent support groups (n = 2) and Multicomponent interventions (n = 2). Studies reported five wellbeing outcomes: quality of life, parent stress, self-efficacy, parenting style and satisfaction. Separate meta-analyses compared each outcome, to test and estimate the summary effect shared by studies reporting each intervention. Statistically significant outcomes were obtained for reducing parent stress via mindfulness training and for improving parent style and satisfaction, through parent education.
Conclusions: Analyses of a small number of studies indicate that parent focussed interventions could be effective in improving parent wellbeing, however further research is needed to determine optimal parent intervention models.

1. Introduction

The current study is a systematic review and meta-analysis of parent focussed interventions and parent wellbeing outcomes. Parent focussed interventions which empower families and enhance mental health and wellbeing are potentially core to achieving optimal outcomes in Autism Spectrum Disorder (ASD) (National Institute for Health & Clinical Excellence (NICE), 2012; Chiang, 2014). ASD clinical guidelines recommend parent-professional partnerships and that parent- mediated interventions be considered for all affected families (National Research Council, 2001; National Institute for Health & Clinical Excellence (NICE), 2011; Scottish Intercollegiate Guidelines Network (SIGN), 2016). Further scrutiny of the evidence underpinning guideline recommendations indicates that there is particularly strong evidence of positive benefits of well-defined socially focussed ASD parent mediated

* Corresponding author.
E-mail address: mrutherford@qmu.ac.uk (M. Rutherford).

https://doi.org/10.1016/j.rasd.2019.101450
Received 8 March 2019; Received in revised form 24 July 2019; Accepted 30 August 2019

interventions for children under 7 years (Oono, Honey, & McConachie, 2013; Pickles et al., 2015). Although a lifelong model of parent training is an aspiration (Matson, Mahan, & Matson, 2009), there is limited evidence about optimal parent interventions for older children (Chiang, 2014; Kuhaneck, Madonna, Novak, & Pearson, 2015; Solomon, Ono, Timmer, & Goodlin-Jones, 2008) and even less evidence in relation to adults (Clifford & Minnes, 2013a; Imms et al., 2016; National Institute for Health & Clinical Excellence (NICE), 2012, 2014). The ideal content, focus and delivery of parent intervention is likely to change over the lifespan and approaches for younger children may not be directly applicable at all ages, therefore in this study we have opted to review evidence available in relation to parent focussed interventions for older children and adults. We selected an 'age 7' cut-off based on current evidence and decisions made in comparable studies for younger children, which used this cut-off and found strong evidence for those under 7, with several RCTs and a Cochrane review reporting child and parent outcomes (Oono et al., 2013) but with markedly weaker evidence above that cut off.

1.1. Terminology

For ease of reading, unless otherwise stated, the terms "parents" refer to parents or carers of individuals with ASD (children or adults) and "older children" are those aged 7 years and over, including adolescents up to age 18. The term "parent-focused" refers to interventions which require parent or carer engagement with professionals and focus on supporting or training parents.

1.2. Parenting and ASD

Parenting an individual with ASD can negatively impact on parent wellbeing. Reported challenges include, decreased parenting efficacy, increased parenting stress (Kuhaneck et al., 2015; Watson et al., 2013) and reduced quality of life (including physical and mental health) which have a reciprocal effect on the autism symptoms observed in their 'child' (Karst & Van Hecke, 2012). This impact, and the increased likelihood that parents will live with their child in adulthood (Karst & Van Hecke, 2012) provides evidence of the need for parent focussed interventions. To take this field forward, we should understand three key things; firstly, which parent interventions are reported for older children and adults. Secondly, which measures effectively evaluate wellbeing outcomes and thirdly how effective are interventions in improving parent wellbeing. Prior to this study we were not able to find answers to these questions.

1.3. Types of parent focused interventions

Five common parent focused intervention sub-types were identified prior to the review (see Table 1), with similarities amongst them permitting meaningful, collective consideration of their effectiveness. They are delivered through expert practitioners teaching parents additional skills and knowledge, to better understand their child or to make helpful changes to daily routines (e.g. Kaminski et al., 2008; Kuhaneck et al., 2015; Cachia et al., 2016) and to improve parent wellbeing through a short term focused opportunity. Parents derive benefits of meeting others in a similar position.

1.4. Measuring wellbeing outcomes

Despite strong evidence to recommend general parenting interventions which impact upon parent wellbeing (Shah, Kennedy, Clark, Bauer, & Schwartz, 2016), we are as yet a long way from a consensus on the best outcome measurement tools. Studies traditionally measured child behaviour and skill, however emphasis is more recently being placed on wellbeing outcomes, which consider the family context (Damiano, Mazefsky, White, & Dichter, 2014; Leadbitter et al., 2018; McConachie et al., 2015). Increased future use of parent wellbeing outcomes in ASD intervention studies is recommended (McConachie et al., 2015). Currently there are challenges in inconsistency and diversity of measures applied.

Reported outcomes from parent focussed interventions include improvements in: parent wellbeing (Ergüner-Tekinalp & Akkök,

Table 1
Types of intervention.

Type of intervention	Description
Parent education, training or coaching programmes	Participants attend short term group training to teach parents about sensory, communication and cognitive differences in ASD and how to combine better understanding with strategies and modifications to their own and their child's behaviour to facilitate participation, positive interaction and learning in natural contexts.
Mindfulness or relaxation training	Participants attend short term group training to learn mindfulness or relaxation techniques with the aim of reducing stress. Such programs may simultaneously involve parents and children.
Parent support groups	ASD parent support groups are commonly available and accessed by parents. These are online or face to face.
Multi-component child and parent intervention models	Manualized, theoretically driven complex interventions which use parent and /or teacher training, alongside older children's intervention activities to develop theory of mind and social interaction skills. Although parents are actively involved, parent outcomes are not reported.
Other	There are some other interventions which did not sit with the above and were the only study of their kind.

2004; Oono et al., 2013; Suppo & Floyd, 2012); communication and shared parent-professional understanding; generalization of learning and behavioural and academic outcomes for children (Benson, 2015; Matson et al., 2009). Prior to the review we identified commonly reported wellbeing measures to date: quality of life, parenting stress, parent self-efficacy, parenting style and satisfaction. This is not an exhaustive list, but given that variety and inconsistency have thus far made it hard to compare data across studies (Kuhaneck et al., 2015), the researchers made the decision to focus on the most commonly identified measures for this review. The relatively large number of different tools used to measure parent wellbeing include both standardized and non-standardized measures. For the purpose of comparison across studies, the decision was made to exclude non-standardized measures and focus on standardized measures likely to have greater reliability and validity.

Child outcomes and health economic analysis were not a focus for this study, although they are relevant to future research on parent-focussed interventions.

1.5. Quality of life

Quality of Life (QoL) is defined with reference to dynamic and complex factors from a range of domains used to assess individual perspectives on participation in daily life through the eye of the experiencer. These are a) macro-societal: how the external environment and socio-political makeup of society provides community based, social support and resources and b) micro-individual: including physical and mental health and wellbeing, psychological outlook, role in society, independence, autonomy and perceived control over life, material and financial circumstances (Brown, Bowling, & Flynn, 2004, p46).

There is consistently reported poor QoL in children and adults with ASD (Van Heijst and Guerts, 2015) and their families (Boehm, Carter, & Taylor, 2015; Ekas, Lickenbrock, & Whitman, 2016; Vasilopoulou & Nisbet, 2016). Although QoL measures specific to ASD are still in development (Eapen & Guan, 2016; Tavernor, Barron, Rodgers, & McConachie, 2013) there is strong evidence that QoL is lower than in typically developing peers. This is unrelated to variables of age, IQ and symptom severity. QoL in families of individuals with ASD was not only lower than for families of typically developing offspring but also lower than families with a member with other disabilities (Eapen & Guan, 2016). There is therefore strong evidence that family QoL and family systems are affected by having a child with ASD (Ekas et al., 2010) and some evidence that well supported families are in a better position to support their children (Russa, Matthews, & Owen-Deschryver, 2015). We can infer that family QoL for parents, carers or spouses of adults with ASD are similarly affected. Notably the reported systematic reviews have not considered QoL in relation to intervention outcomes.

1.6. Parenting stress

QoL and parenting stress are closely related constructs. Over 90% of parents of children with ASD experience substantial parenting stress (Nikmat, Ahmad, OON, & Razali, 2008), which is higher than for parents of typically developing children or children with other disabilities (Bendixen et al., 2011; Cachia, Anderson, & Moore, 2016; Watson et al., 2013). Variables associated with increased stress include severity of child behavioural difficulties, need for high levels of vigilance, difficulty in daily routines and social difficulties. The earlier interventions starts, the greater the reduction in parent stress (Mcconachie & Diggle, 2007).

1.7. Parent self-efficacy

Parent self-efficacy is another QoL related concept (Kaminski, Valle, Filene, & Boyle, 2014) affecting the quality of caregiving (Benn, Akiva, Arel, & Roeser, 2012), caregiver sense of competence (Kaminski et al., 2008) and parental confidence (Whittingham, Sofronoff, Sheffield, & Sanders, 2009) commonly measured in the Parenting Sense of Competence Scale (Grindle, Kovshoff, Hastings, & Remington, 1978). An interrelationship exists between parent self-efficacy and child education success, behaviour and wellbeing (Sanders & Woolley, 2005; Sofronoff, Leslie, & Brown, 2004; Whittingham, Sofronoff, Sheffield, & Sanders, 2009; Benn et al., 2012; Kaminski et al., 2008).

1.8. Parenting style and parent satisfaction

These have been measured separately in the studies although they could be considered to overlap with both QoL and parent self-efficacy.

1.9. Theoretical framework

Effective examination of emergent complex interventions involving parents of children with ASD necessitates a coherent theoretical framework connecting interventions and outcomes (de Bruin, Blom, Smit, van Steensel, & Bögels, 2013; Kuhaneck et al., 2015: McConachie et al., 2015). A number of ecological systems frameworks take account of the interaction between child and environment (Ogletree, Oren, & Fischer, 2007; World Health Organization, 2007; Kielhofner, 2008; Michie, van Stralen, & West, 2011; Rubin, Prizant, Laurent, & Wetherby, 2013; McConachie et al., 2015). Language and constructs used are by no means agreed (Karst & Van Hecke, 2012), however our capacity to understand and develop effective interventions (Pickles et al., 2015) will develop out of greater consensus on theoretical frameworks, complex mechanisms for change and the dynamic relationships between these. The review will consider key components for development of a future framework.

1.10. Hypothesis

We hypothesised that parent wellbeing can be improved through ASD parent focused interventions for older children and that the focus of interventions and outcome measures would be heterogeneous but overlapping in focus.

1.11. Aims

1 Identify all Randomised Controlled Trials (RCTs) and experimental studies which report standardised wellbeing outcome measures to test effectiveness of ASD parent focused interventions for parents of older children or adults and determine:
   a) the number and range of ASD interventions reported
   b) the type and range of wellbeing outcomes reported
2 Systematically review evidence of the relationship between such interventions and measured parent wellbeing outcomes to assess the quality of studies; to determine the total number of participants included and their characteristics
3 To identify whether parent focused interventions are effective in improving wellbeing through meta-analysis and determine the effect size in studies measuring parent intervention outcomes to identify areas where new trials are needed.

2. Method

2.1. Selection criteria

Studies met the following inclusion criteria devised using the PICOS approach (Liberati et al., 2009): (1) An intervention study focussed on parents/carers of children (7–18) or adults (over 18) with Autism Spectrum Disorder (2) the study reports parent outcomes using standardised assessments of parent wellbeing (3) the quantitative research design includes a non-intervention or pre-post comparison group (4) the paper was published in a peer reviewed journal, in English. Qualitative studies, review papers, non intervention studies and intervention studies without parent participation were excluded, as were parent focussed interventions for individuals without ASD or for younger children. Where participants were across the age range, studies where the mean age was below 7 were excluded and studies with the mean age above 7 were included. Grey literature was excluded, for example, technical reports, dissertations or unpublished documents.

2.2. Search strategy

In September 2016, a comprehensive search of electronic databases, including: MEDLINE, PsycINFO, CINAHL, and the Cochrane Database was conducted as part of a systematic review examining outcomes of parent focussed interventions for parents of older children or adults with ASD. In addition, selected journals were hand searched and reference lists of relevant articles were examined to identify additional studies meeting the criteria for inclusion. Search strings used and a full list of electronic databases are provided in Table 2.

2.3. Study selection

Electronic and hand searches were completed and duplicates removed. Two reviewers assessed studies for relevance through the process outlined in Fig. 1. Firstly, titles and then abstracts were screened. Full text articles of remaining studies were reviewed to identify those meeting inclusion criteria. Reasons for exclusion were clearly stated. Where it is stated that no QoL related outcomes were identified – this term was used to refer to wellbeing outcomes defined above. Reference lists of included studies were also

Table 2
Key words and databases used to identify studies, which focused on interventions for families of children and adults with an ASD.

Key words:	**Databases searched**
Family, carer, mother, mum, father, dad or parent	PsycINFO
Child, adolescent or adult	Scopus®
Autism, ASD or Asperger's	Social Sciences Citation Index
Intervention, training, education, support, program	ERIC
Combinations of Key words were used in each search string. The following search string was among those which retrieved the highest number of hits:	Science Direct
	Science Citation Index
((Famil* or Care* or Mother or Mum or Father or Dad or Parent*)) AND ((child* or adolescent* or adult*)) AND ((Autism or ASD or Asperger*)) AND ((intervention* or training* or education or support or program*))	CINAHL Plus with Full Text
	MEDLINE
	Family Studies Abstracts
	British Library EThOS
	ClinicalTrials.gov
	PsycARTICLES
	Cochrane Database of Systematic Reviews
	Additional relevant databases available within the DISCOVER search engine

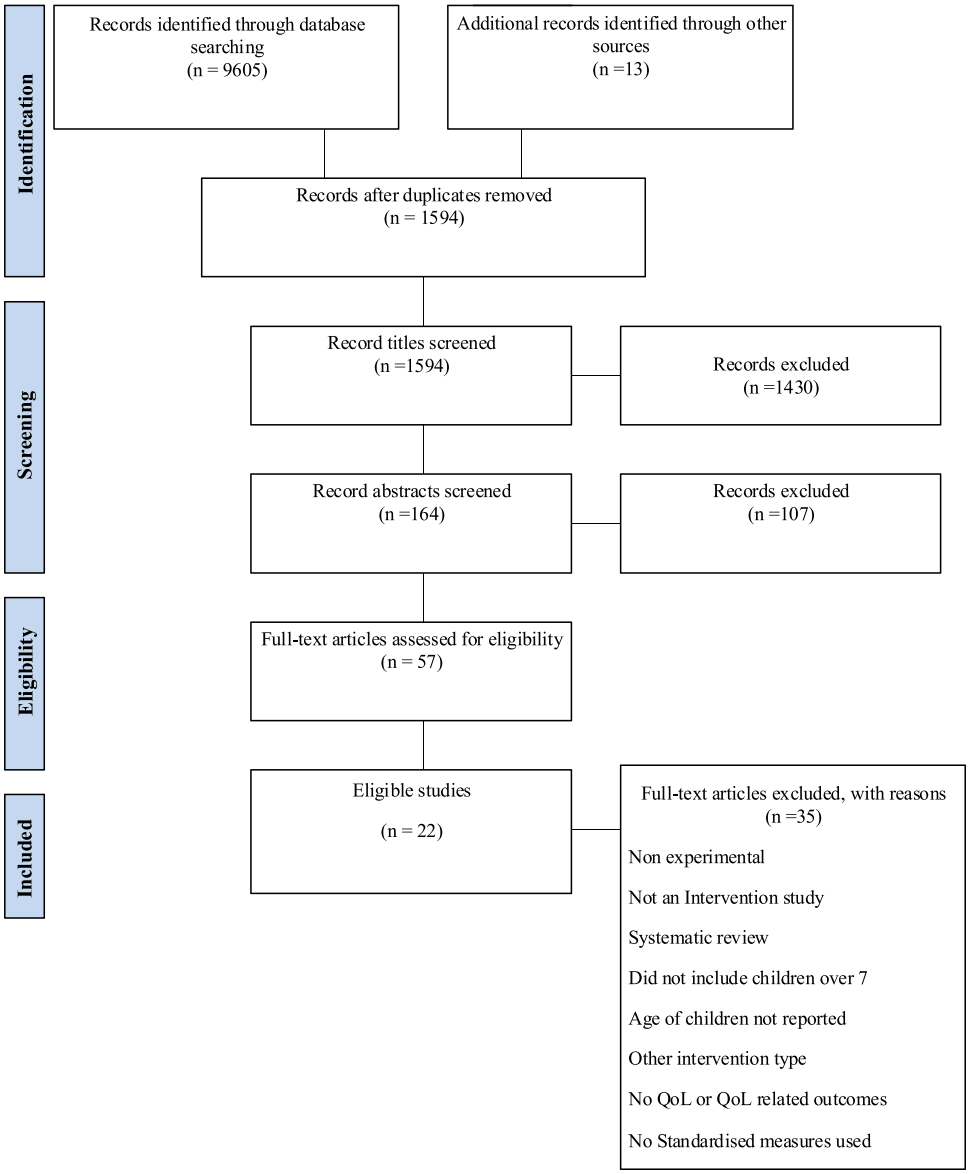

Fig. 1. PRISMA Flow Diagram.
*Authors were contacted when age of diagnosis was not reported. Studies were only excluded if authors were unable to provide this information. * The high duplicate count is attributed to a comprehensive search of a number of relevant databases to ensure we found all relevant studies, see Table 2.

reviewed to ensure relevant publications were not missed. Disagreements between reviewers were dealt with through discussion and reaching consensus.

2.4. Quality assessment

Methodological quality of selected studies was assessed (see Table 3), including review of risk of bias, using the Effective Public Health Practice Project (EPHPP) Quality assessment tool (Thomas, Ciliska, Dobbins, & Micucci, 2004) designed for assessing the quality and bias of quantitative studies. Each paper was assessed by two post graduate researchers, who received in-house training in quality assessment. Consensus was reached through discussion.

2.5. Data extraction

A data extraction tool was used to systematically record data from included studies: Authors, study design, information about

Table 3
Results of duplicate quality assessment of studies, using the Effective Public Health Practice Project (EPHPP) Quality Assessment Tool for Quantitative Studies (N = 22).

Study authors and date	Country	Study design	Intervention name (where available)	Manualised	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawal and drop-out	Quality assessment rating[*]	Overall score/12[#]
Benn et al. (2012)	USA	RCT	Mindfulness training	Yes	2	1	1	0	1	2	Moderate	8
Bendixen et al. (2011)	USA	Quasi-experimental	In-Home Parent Training	No	2	2	N/A	0	1	1	Moderate	6
de Bruin et al. (2015)	Netherlands	Cohort	Mindfulness training	Yes	2	2	N/A	0	1	1	Moderate	6
Clifford and Minnes (2013b)	USA	Cohort	Parent Education/ Training	No	0	2	N/A	0	1	0	Weak	3
Craig et al. (2013)	USA	CT	Online Parent Support	No	0	1	1	0	1	0	Weak	6
Elfert and Mirenda (2015)	Canada	Cohort	Parent Support Group	No	2	2	N/A	0	1	1	Moderate	6
Gibaud-Wallston and Wandersman (1978)	USA	RCT	Mindfulness and parent education/ training programs	Yes	2	1	1	0	1	2	Moderate	8
Hare, Pratt, Burton, Bromley, and Emerson (2012)	Greece	Case Series	Relaxation Training	Yes (CD format)	2	0	N/A	0	1	0	Weak	3
Kaminski et al. (2008)	China	RCT	Parent Education Program	Not stated	2	1	1	2	1	1	Strong	10
Patra, Arun, and Chavan (2015)	India	Cohort	Parent Psychoeducation Programme	No[**]	2	2	N/A	2	1	0	Moderate	5
Roberts and Pickering (2010)	Wales	Cohort (pilot)	Parent Training Program (Incredible Years)	Yes	2	2	N/A	2	1	0	Moderate	5
Ruiz-Robledillo, Sariñana-González, Pérez-Blasco, González-Bono, and Moya-Albiol (2015)	Spain	Quasi-experimental	Mindfulness-Based Program	No[***]	2	2	1	2	1	0	Moderate	7
Samadi, McConkey, and Kelly (2013)	Iran	Cohort	Parent Education/ Training Program	No[**]	2	2	1	0	1	1	Moderate	8
Singh et al. (2014)	USA	Cohort	Mindfulness Based Parent Training	No	2	2	N/A	0	1	0	Weak	4
Smith, Greenberg, and Mailick (2012)	USA	Cohort	Multi-family group psychoeducation	Yes	0		N/A	0	1	0	Weak	1
Stuttard, Beresford, Clarke, Beecham, and Curtis (2015)	UK	CT	Riding the Rapids (parent support intervention)	Yes	2	1	1	0	1	1	Moderate	9
Stuttard et al. (2015)	UK	Cohort	Managing your child's behavior to promote better sleep	Yes	1	2	N/A	0	1	2	Moderate	9

(*continued on next page*)

Table 3 (*continued*)

Study authors and date	Country	Study design	Intervention name (where available)	Manualised	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawal and drop-out	Quality assessment rating*	Overall score/12#
Stuttard, Beresford, Clarke, Beecham, and Morris (2016)	UK	CT	Cygnet Parenting Support Programme	Yes	2	1	1	2	1	0	Moderate	8
Tellegen and Sanders (2014)	Australia	RCT	Primary Care Stepping Stones Triple P	Yes	2	1	1	2	1	1	Strong	10
Todd et al. (2010)	UK	Cohort	Parent Training Program	Not yet	2	2	N/A	0	2	1	Moderate	5
Weiss, Viecili, Sloman, and Lunsky (2013)	Canada	Cohort	Social Skills Intervention for children and parents	Yes (unpublished)	2	2	N/A	0	1	1	Moderate	6
Whittingham et al. (2009b)	Australia	RCT	Behavioural Family Intervention	Yes	1	1	1	0	1	1	Moderate	10

* Studies are rated to give an aggregate overall score of 'strong', 'moderate' or 'weak' ('strong' if no 'weak' individual-scale ratings are designated, 'moderate' if one, and 'weak' if two or more).
# Ratings of 'strong' are assigned two points, 'moderate' one point, and 'weak' no points, and then summed to provide additional differentiation between studies.
** not formally but written down for replication.
*** well described in publication.

participants and control groups, intervention details, outcome measures used, results and statistical analyses used. Extracted data were summarized in evidence tables.

2.6. Meta-analysis and computation of effect sizes

Data were extracted from each study and a standardized mean difference was identified as a summary descriptive statistic across studies. This is an expression of the "size of the intervention effect in each study relative to the variability observed in that study" (Ji et al., 2014) which is used to demonstrate the observed treatment effect. We then calculated a weighted average of the summary statistics estimated in the individual studies to obtain an estimate of the pooled treatment effect across all studies (Borenstein, Hedges, Higgins, & Rothstein, 2009; Ji et al., 2014). A random effects model was fitted, testing the null hypothesis that the mean effect across all studies is 0.0.

3. Results

3.1. Systematic review

We identified research studies which reported standardised wellbeing measures to test effectiveness of ASD parent focussed interventions. Of the 57 articles reviewed as full text, 22 met inclusion criteria and 35 were excluded for reasons given in Fig. 1. Twenty two different interventions were reported and 20 different wellbeing measures.

3.2. Research design and quality

The results of quality assessment of included studies (Table 3) identified 5 RCTs, 3 non randomised control trials (CTs) and 14 cohort studies with pre-post measures. Studies were evaluated by two independent researchers within the team and where there was disagreement consensus was reached through discussion. Two studies given a *strong* quality rating, 15 *moderate* and 5 *weak*.

3.3. Characteristics of key studies

Our systematic literature searches of English language international peer-reviewed literature identified 22 studies, which met criteria (Table 3). In addition, two systematic reviews report on aspects of parent wellbeing outcomes for some types of ASD parent interventions – those delivered by Occupational therapist and Mindfulness interventions (Cachia et al., 2016; Kuhaneck et al., 2015). These reviews were not directly included. Selected studies were used firstly for systematic review and secondly for meta-analysis.

Included studies used heterogeneous interventions and outcomes measures which reported parent wellbeing outcomes on a continuous scale, where decreased stress but increase in other measures are good outcomes. Data were extracted for these outcomes, for each type of intervention and each study design (for randomised (n = 5) and non-randomised (n = 3) controlled trials and for single cohort studies with a pre-post design (n = 14). For CTs, outcomes were stated as means and standard deviations of the experimental and control groups calculated at baseline (pre-treatment) and at post-treatment.

3.4. Children and adults with ASD: characteristics

'Children'(n = 550) were aged between 3 and 23 years, with 3 studies including parents of young adults (Benn et al., 2012; de Bruin et al., 2015; Singh et al., 2014). No studies involved parents of adults over 24 years.

3.5. Parent characteristics

Participants were parents/ carers of children or adults with ASD. All studies included less than 80 parents. Findings were reported on a total of 600 parents, 3 grandparents and 4 caregivers. Other demographic variables are summarised in Table 4.

3.6. Intervention characteristics

Interventions reported were heterogeneous and characterized into 4 main groups: Parent education, training and coaching (n = 12), Mindfulness and relaxation (n = 6), Multi-component parent/ child interventions (n = 2) and Support groups (n = 2). No specific intervention was repeated more than once. Thirteen were manualised interventions, 4 others included comprehensive descriptions to allow for replication, 5 had no manual, or description or this was not stated (see Table 3). Interventions were time limited with weekly attendance and ranged from 4 to 15 weeks, with the exception of support groups which were not time limited.

3.7. Measures

Twenty two studies were excluded because they did not use standardised outcome measures of wellbeing. Across the 22 included studies, which used at least one standardised measure, 20 different measures were used (see Table 5).

Table 4
Participants Demographics reported in 22 key studies.

Characteristics	No.	Number and percentage of studies where reported	
Children with a reported ASD diagnosis*	550	21/22	95.5%
Other primary diagnosis (where reported)	17	2/22	9.0%
Comorbidity diagnosis (where reported)	40	5/22	22.7%
Male	405	18/22	81.8%
Female	85	14/22	63.7%
Age range	2-23 >	20/22	90.9%
Range of children per household	1-8	11/22	50%
The average was 2 or more children per household in 7/11 studies			
Total Parents	600	21/22	95.5%
Mothers	481	18/22	81.8%
Fathers	119	18/22	81.8%
Grandparent	3	3/22	13.6%
Other (not specified)	4	1/22	4.5%
Age range in years (where reported)	27-65	8/22	36.3%
Mean age range (where reported)	33-53	4/22	18.1%
Marital Status reported in N = studies **			
Married or living in a common law relationship	373	13/22	59.0%
Lone parent, divorced or other	55	6/22	27.3%
Education History reported in N = 18/23 studies			
High School Education (number of parents or families)	172 + 1 family	18/23	78.2%
Higher Education (number of parents or families)	325 + 11 families		
Employment status was reported in 8/22 studies			
Those in employment	134	8/23	35%
Those in unemployment	95		

Due to the way data was reported:

* Unable to identify the number of children with a diagnosis of ASD from the other participants in Todd et al. (2010).

** Unable to identify numbers per marital status of participants in 2/15 studies (Benn et al., 2012; Stuttard et al., 2016).

Table 5
ASD parent intervention outcomes and measures.

Type of outcome	Abbreviated names given to measures used	Studies
Quality of Life	WHO-5 (World Health Organisation (Five) Wellbeing Index) WHO-QOL (World Health Organisation Quality of Life instrument) HR-QOL SF-36 (Health Related Quality of Life) GHQ (General Health Questionnaire)	de Bruin et al. (2015); Clifford and Minnes (2013b); Gibaud-Wallston and Wandersman (1978); Kaminski et al. (2008); Roberts and Pickering (2010); Ruiz-Robledillo et al. (2015); Samadi et al. (2013)
Mindfulness	FFMQ (Five Facet Mindfulness Questionnaire) MAAS (Mindful Attention and Awareness Scale)	Benn et al. (2012); de Bruin et al. (2015); Gibaud-Wallston and Wandersman (1978)
Parent stress	PSS (The Perceived Stress Scale) PSI/ PSI SF/ PSI-C/ PSI 4-SF (versions of the Parenting Stress Index) FSC (Family Stress and Coping Interview) HADS (Hospital Anxiety and Depression Scale)	Benn et al. (2012); Bendixen et al. (2011); de Bruin et al. (2015); Clifford and Minnes (2013b); Craig et al. (2013); Ferraioli and Harris (2013); Gibaud-Wallston and Wandersman (1978); Hare et al. (2004); Patra et al. (2015); Samadi et al. (2013); Singh et al. (2014); Solomon et al. (2008); Todd et al. (2010)
Parent self-efficacy	EPS (Everyday Parenting Scale) PSOC (Parenting Sense of Competence Scale) FACES-II (Family Adaptability and Cohesion Evaluation Scales –II) WCQ (Ways of Coping Questionnaire) GSE (General Self-efficacy) FES (Family Empowerment Scale)	Benn et al. (2012); Bendixen et al. (2011); Kaminski et al. (2008); Stuttard et al. (2015), 2016); Weiss et al. (2013)
Parenting style	PS (Parenting Style)	de Bruin et al. (2015); Tellegen and Sanders (2014); Whittingham et al. (2009b)
Parent satisfaction	CSQ (Client Satisfaction Questionnaire) BPS (Being a Parent Scale) PSOC (Parenting Sense of Competence Scale)	Stuttard et al. (2015); Tellegen and Sanders (2014); Whittingham et al. (2009b)

Table 6
Summary of eligible single group non randomized intervention studies (single group pre-post trials) measuring Quality of Life and Quality of Life related outcomes in parents (n = 14/22).

Intervention: Parent Education or Training

Author (Publication Year)	Participant	Sample Size	QoL & QoL related outcomes (Parents)	Measures	Effect Size*
Outcome: Quality of Life					
Clifford and Minnes (2013b)	Mothers of Chinese American children with ASD	9	Global Quality of Life	WHOQOL-Brief-Physical WHOQOL-Brief-Environment	1.10 0.62
Roberts and Pickering (2010)	Parents of boys with ASD	8	General Wellbeing	GHQ-30	Data reported insufficient to calculate an effect size
Samadi et al. (2013)	Parents who lived with their child having a confirmed diagnosis of ASD	13 fathers; 24 mothers	General Wellbeing	GHQ	Data reported insufficient to calculate an effect size
Outcome: Stress					
Bendixen et al. (2011)	Fathers Mothers	19 19	Parent Stress Parent Stress	PSI Total PSI Total	−0.29 −0.32
Clifford and Minnes (2013b)	Mothers of Chinese American children with ASD	9	Parent Stress	PSI-child domain PSI-parent domain	0.88 0.89
Samadi et al. (2013)	Parents who lived with their child having a confirmed diagnosis of ASD	13 fathers; 24 mothers	Parent Stress	PSI - SF	Data reported insufficient to calculate an effect size
Patra et al. (2015)	Parents of children diagnosed with ASD	10 fathers; 8 mothers	Parent Stress	Family interview for stress and coping in mental retardation	Data reported insufficient to calculate an effect size
Todd et al. (2010)	Parents/carers of children aged 4-11 diagnosed with LD, autism and ASD	22 22	Anxiety Depression	HADS HADS	−0.75 −0.76
Outcome: Self Efficacy					
Stuttard et al. (2015)	Parents of children with intellectual disabilities including children with ASD	19 mothers; 4 fathers	Satisfaction Efficacy	PSOC	0.52 0.37

Intervention: Mindfulness training

Author (Publication Year)	Participant	Sample Size	QoL & QoLrelated outcomes (Parents)	Measures	Effect Size
Outcome: Quality of Life					
de Bruin et al. (2015)	Parents of adolescents with ASD	11 fathers; 18 mothers	Global Quality of Life	WHO-5	0.34
Ruiz-Robledillo et al. (2015)	Parents of adolescents with ASD	1 father; 5 mothers	Perceived General Health Total	GHQ-28	−1.65
Outcome: Stress					
de Bruin et al. (2015)	Parents of adolescents with ASD	11 fathers; 18 mothers	Stress	PSI-C	−0.21
Hare et al. (2004)	Mothers of children with autism	11	Stress	PSS-14, PSI-SF	−0.63 **

(*continued on next page*)

Table 6 (*continued*)

Intervention: Mindfulness training					
Author (Publication Year)	Participant	Sample Size	QoL & QoLrelated outcomes (Parents)	Measures	Effect Size
Singh et al. (2014)	Mothers of adolescents with Asperger's	3	Stress	PSS-10	−2.72
Ruiz-Robledillo et al. (2015)	Parents of adolescents with ASD	1 father; 5 mothers	Depressive Symptomatology Somatic Symptoms	BDI ESS-R	−1.31 −2.79
Outcome: Parenting Style					
de Bruin et al. (2015)	Parents of adolescents with ASD	11 fathers; 18 mothers	Laxness Verbosity Overreactivity	PS-Laxness PS-Verbosity PS-Overreactivity	0.17 −0.31 −0.12
Intervention: Parent support groups/ multi-component child and parent intervention					
Author (Publication Year)	Participant	Sample Size	QoL & QoL related outcomes (Parents)	Measures	Effect Size
Outcome: Quality of Life					
Weiss et al. (2013)	Parents	25 26	Psychological Acceptance Family Empowerment	AAQ-II FES	0.47 0.23
Outcome:Stress					
Ferraioli and Harris (2013)	Fathers of children with ASD	12	Parenting Stress Depression	PSI-SF-4 BDI-II	−0.21 −0.03
Smith et al. (2012)	Families of adolescents with ASD	8 fathers; 10 mothers	Parent Stress Rating		0.17

*Effect size is reported is a standardized mean difference between post and pre outcome scores.
Children of parents in Todd et al. (2010) had a range of disabilities and number of children with ASD was not reported.
Six parents were compared with 7 non caregivers in Ruiz-Robledillo et al. (2015).
** Effect size reported is the correlation r.

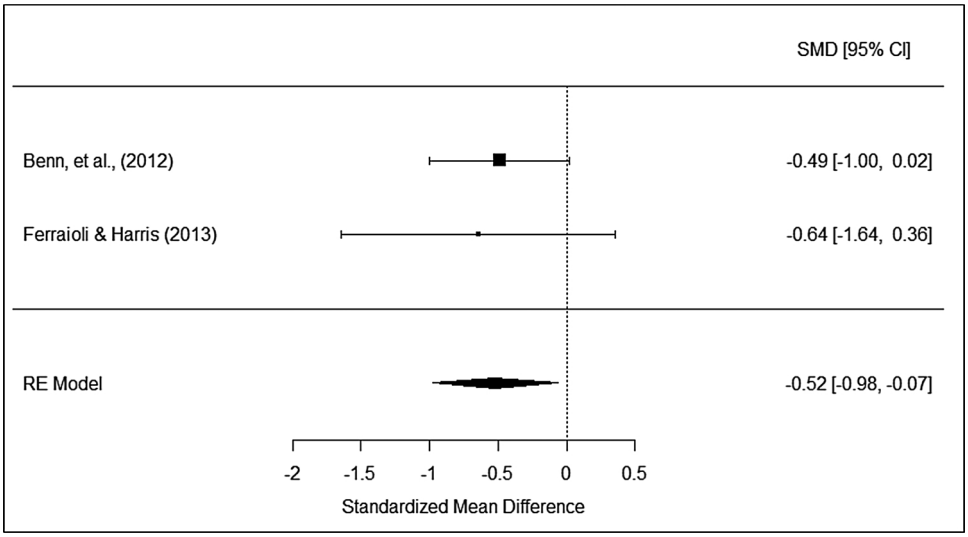

Fig. 2. Forest plot for the outcome of parent stress following mindfulness and relaxation training.
Statistically significant medium (negative) effect size of -0.52 with confidence interval (-0.98, -0.07) observed for stress. Mindfulness training seems to be an effective intervention for reducing stress among participants. Heterogeneity statistic $I^2 = 0.00\%$ ($p = 0.79$) i.e. not significant

3.8. Non randomised studies

For pre-post trials, means and standard deviations were reported for a single group of participants (mostly) and these were calculated prior to the treatment and post treatment. Essential information for calculation of effect size, such as correlations between pre-test and post-test observations were not reported in three studies, nor the standard deviations of the difference in observations. Variance could not be calculated and these studies could not be included in the meta-analysis (see Table 6).

Since the significance of the effect size could not be estimated and meta-analysis could not be applied, it is not possible to draw conclusions about effectiveness.

3.9. Meta-analysis

A separate meta-analysis model was fitted for each outcome and each type of intervention, which results in 7 models. Seven studies were included (5 RCTs and 3 CTs), with a total sample size of 351 parents/caregivers. Outcomes investigated were parent stress, parenting style (laxness, verbosity and over-reactivity), parent self-efficacy and parent satisfaction. The common effect size calculated across studies is the standardised mean difference, Hedges *g*. A Random effects model was fitted for each outcome. Forest plots from fitting the models are presented below.

3.10. Parent stress

3.10.1. Intervention: mindfulness

One random effects model is fitted involving 2 RCTs and 74 participants in total (59 + 15).

For the outcome of parent stress, we calculated a medium negative effect size that is statistically significant, this suggests that with this small sample, the intervention is effective in reducing parent stress. For the outcome of mindfulness, a significant effect size was not obtained. The intervention is not effective in improving mindfulness of participants with measures used (Fig. 2).

3.11. Parenting style – laxness, verbosity and overreactivity

3.11.1. Intervention: parent education and training

Three random effects models are fitted (one for each outcome). Each model involves 2 RCTs and 123 participants in total (64 + 59) (Fig. 3).

For the outcomes of parenting style (laxness, verbosity and over reactivity), a significant large negative effect size was obtained. This intervention seems to be highly effective in reducing these behaviours in parents.

3.12. Parent self-efficacy and satisfaction

3.12.1. Intervention: parent education and training

Two random effects models are fitted (one for each outcome). The model for self efficacy involves 5 studies (2 non RCTs and 3

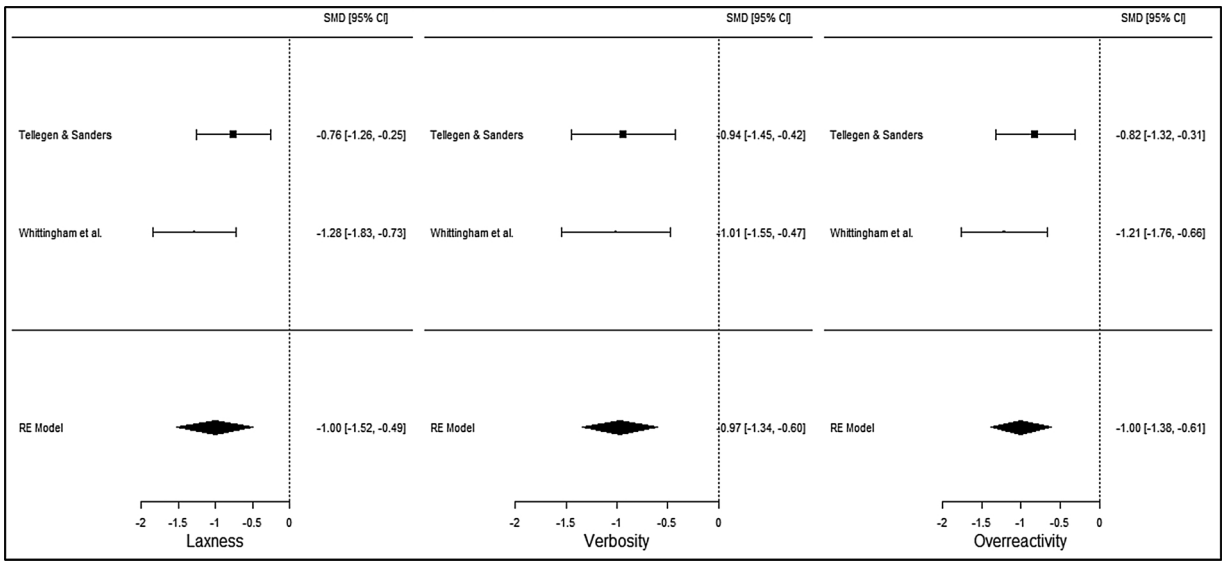

Fig. 3. Forest plot for the outcomes of parenting style following parent education and training.
Statistically significant large (negative) effect sizes for all three parenting styles – laxness [-1.00 with confidence interval (-1.52, -0.49)], verbosity [-0.97 with confidence interval (-1.34, -0.60)] and overreactivity [-1.00 with confidence interval (-1.38, -0.61)]. Parent education and training seems to be an effective intervention for reducing laxness, verbosity and overreactivity among participants, thereby improving their parenting styles. Heterogeneity statistics I2 = 47.20% (p = 0.17) for laxness, I2 = 0.00% (p = 0.84) for verbosity and I2 = 6.64% (p = 0.30) for over-reactivity. All three are non-significant.

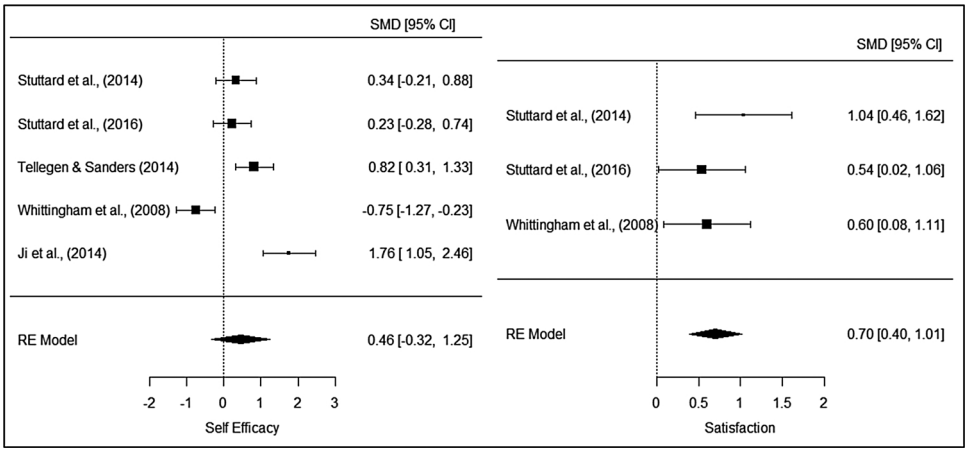

Fig. 4. Forest plot for the outcomes of parent self-efficacy and satisfaction following parent education and training.
Medium effect size of 0.46 with confidence interval (-0.32, 1.25) observed for self efficacy, however it is not statistically significant. Statistically significant large effect size of 0.7 with confidence interval (0.39, 1.01) observed for satisfaction. Parent education and training seems to be an effective intervention for increasing satisfaction among participants, but does not seem to have any effect on self efficacy. Heterogeneity statistics I2 = 90.18% (p < 0.00) for self efficacy i.e. it is significant; I2 = 0.00% (p = 0.40) for satisfaction i.e. non-significant.

RCTs) and 277 participants in total (54 + 58 + 64 + 59 + 42). The model for satisfaction involves 3 studies (2 non RCTs and 1 RCT) and 171 participants in total (54 + 58 + 59) (Fig. 4).

A non-significant effect size was found for the outcome of self-efficacy which indicates that the intervention may not be effective in improving self-efficacy in parents. For parent satisfaction, a large positive significant effect size obtained which reveals that the intervention is successful in improving satisfaction among parents.

3.13. Support groups

Only two studies used this intervention type and they could not be included in a meta-analysis due to essential information for calculating effect size being missing. These were either face to face or online supports for parents that did not involve training or coaching (Ferraioli & Harris, 2013 & Craig et al., 2013) (see Table 3).

3.14. Results summary

Statistically significant outcomes were obtained for reducing parent stress (via mindfulness training) and improving parent style, and satisfaction (via parent training and education). Effectiveness of support groups could not be analysed as there was only one controlled trial (Craig et al., 2013) and one single group pre-post study Ferraioli & Harris, 2013).

4. Discussion

This study adds useful evidence in an emerging field of research about parent focused interventions for older children and adults with ASD, suggesting that these can improve parent wellbeing. Wellbeing is reduced in parents of individuals with ASD across the lifespan (Van Heijst & Geurts, 2015; Ekas et al., 2010). Parent-focused interventions are recommended for parents of individuals with ASD over the age of 7 years (Scottish Intercollegiate Guidelines Network (SIGN), 2016; National Institute for Health & Clinical Excellence (NICE), 2012, 2014) with the recognition that more research is needed (Kuhaneck et al., 2015). This systematic review identified 22 studies, which met inclusion criteria and four types of intervention (mindfulness or parent relaxation training; parent education, parent support groups and multi-component parent-child interventions). Initial investigations reveal that there are some positive outcomes from parent focussed interventions, however due to the lack of data in this field, meta-analysis can be performed but is not robust enough to draw strong conclusions at this point. Further research needs to be conducted.

The following could be considered in designing future studies of higher quality. Study quality is generally low, with small sample sizes, no replication studies, significant heterogeneity in interventions used and outcomes measured, with very few RCTs. In future, full reporting of statistics should be done, for example means and standard deviations of outcome scores for each group and correlation coefficient between the scores, for single group pre-post trials.

Few intervention studies apply manualised, well-defined interventions, together with standardised parent wellbeing outcome measures. There is a gap in provision for parents of adults and future health economic analysis is recommended.

5. Limitations

The small number of high quality studies, relatively small sample size and the heterogeneity reported, limits and the potential to generalise findings. The number of studies included in each meta analysis is very small, ranging between 2–5, which may result in miscalculation in the average population effect size and average sampling error. Due to the small number of studies we included randomised and non-randomised designs into the same model for 2 outcomes (satisfaction and efficacy). With a limited number of studies, the confidence intervals from random-effects models are wider and statistical power lower leading to less robust results. Potential sources of heterogeneity could not be analysed due to lack of data for relevant variables reported in included studies. Due to the small number of studies (2, 2 and 5) available for each meta-analysis, assessment of publication bias and sensitivity analyses could not be performed (Lin et al., 2018).

6. Wellbeing outcomes

However, despite these limitations there are still some useful conclusions about autism intervention research and how outcomes are measured. The emerging, theory driven, complex interventions which combine parent training with child focussed work in school settings, have not yet included standardised parent wellbeing measures. This would be of future interest (Winner & Crooke, 2009; Laugeson Elizabeth, Fred, Catherine, & Dillon Ashley, 2009).

Five parent wellbeing outcomes were reported (QoL, parent stress, efficacy, style and satisfaction) using 20 different standardised assessments, none of which were specifically devised for families with a child with ASD (Eapen & Guan, 2016; Tavernor et al., 2013). Whilst wellbeing measures have shown positive outcomes immediately following intervention (McConachie et al., 2015; Leadbitter et al., 2018), there is less evidence of maintenance at follow up. The review findings suggest a need for more consistent use of standardised parent wellbeing outcome measures in ASD intervention studies. There is also a need to develop a measurement tool that is fit for purpose with this population and based on a robust theoretical model which takes account of family context, mechanisms of change in particular interventions and the specific outcomes related to these. The study by Leadbitter et al. (2018) is a promising development published since this review was completed, describing the development of a new parent wellbeing measure – 'the autism family experience questionnaire'.

MRC guidance on complex interventions advises the development of a robust theoretical framework as the basis for good quality and robust intervention research. No consensus conceptual framework was identified in the review. However we were able to identify factors commonly arising as mechanisms and variables moderating parent wellbeing and outcomes measured parents prior to, during and after interventions. These are discussed further below. The core concept of parent participation in meaningful, pleasurable and socially expected activities is closely linked to wellbeing (Eapen & Guan, 2016), such as leisure time (Gika et al., 2012); childcare; employment and financial independence (Montes & Halterman, 2008a and 2008b). Participation is potentially affected by having a child with ASD and frameworks previously applied in relation to children (Karst & Van Hecke, 2012; MacKay et al., 2018) could equally apply to parents. Intervention outcomes are relative to pre-existing factors and may arise as a result of: feeling more informed, confident and skilled; the presence of external supports; the experience of feeling in control, feeling supported and through participation in activities of peers and the community.

Pre-existing parent stress and QoL could influence choice of intervention and frequency of attendance (Benn et al., 2012), in turn

influencing outcomes. In one study, attrition rates were attributed to wellbeing because those who dropped out, scored lower at baseline in mindfulness, personal growth and higher in stress, and anxiety (Benn et al., 2012).

Further consideration should be given to the development of a framework which takes account of factors drawn from the systematic review with a focus on participation, wellbeing, the nature of ASD and the impact on families (World Health Organization, 2007; Michie et al., 2011).

7. Implications

This is an exciting and emerging field with the potential for positive impact on daily lives of individuals with ASD and their families (e.g. those associated with parent stress, developing parent style and increasing satisfaction in this population). This analysis suggests the need for further study to understand the complex inter-related mechanisms affecting outcomes. There is a continued need for further ASD parent intervention studies for older children and adults above their mid-20s (MacKay et al., 2018) using theory driven, manualised interventions, which apply standardised parent wellbeing measures, including ASD specific measures. For interventions with positive effects reported, there is a need for replication studies and RCTs.

References

Bendixen, R. M., Elder, J. H., Donaldson, S., Kairalla, J. A., Valcante, G., & Ferdig, R. E. (2011). Effects of a father-based in-home intervention on perceived stress and family dynamics in parents of children with autism. *American Journal of Occupational Therapy, 65*(6), 679–687.

Benn, R., Akiva, T., Arel, S., & Roeser, R. W. (2012). Mindfulness training effects for parents and educators of children with special needs. *Developmental Psychology, 48*(5), 1476.

Benson, P. R. (2015). Longitudinal effects of educational involvement on parent and family functioning among mothers of children with ASD. *Research in Autism Spectrum Disorders, 11*, 42–55.

Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 120*(5), 395–411.

Borenstein, M., Hedges, L.V., Higgins, J. and Rothstein, H.R., 2009. John Wiley & Sons, Ltd.

Brown, J., Bowling, A., & Flynn, T. (2004). *Models of quality of life: A taxonomy, overview and systematic review of the literature.* May*European forum on population ageing research*.

Cachia, R. L., Anderson, A., & Moore, D. W. (2016). Mindfulness, stress and wellbeing in parents of children with autism spectrum disorder: A systematic review. *Journal of Child and Family Studies, 25*(1), 1–14.

Chiang, H. M. (2014). A parent education program for parents of Chinese American children with autism spectrum disorders (ASDs) a pilot study. *Focus on Autism and Other Developmental Disabilities, 29*(2), 88–94.

Clifford, T., & Minnes, P. (2013a). Who participates in support groups for parents of children with autism spectrum disorders? The role of beliefs and coping style. *Journal of Autism and Developmental Disorders, 43*(1), 179–187.

Clifford, T., & Minnes, P. (2013b). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(7), 1662–1675.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: The new Medical Research Council guidance International. *Journal of Nursing Studies, 59*, 587–592.

Damiano, C. R., Mazefsky, C. A., White, S. W., & Dichter, G. S. (2014). Future directions for research in autism spectrum disorders. *Journal of Clinical Child & Adolescent Psychology, 43*(5), 828–843.

de Bruin, E. I., Blom, R., Smit, F. M., van Steensel, F. J., & Bögels, S. M. (2015). MYmind: Mindfulness training for Youngsters with autism spectrum disorders and their parents. *Autism, 19*(8), 906–914.

Eapen, V., & Guan, J. (2016). Parental quality of life in autism spectrum disorder: Current status and future directions. *Acta Psychopathologica, 2*(1), 1–14.

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and wellbeing in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(10), 1274–1284.

Elfert, M., & Mirenda, P. (2015). Evaluation of a support group for fathers of children with autism spectrum disorder. *Canadian Journal of Counselling and Psychotherapy/Revue canadienne de counseling et de psychothérapie, 49*(2).

Ergüner-Tekinalp, B., & Akkök, F. (2004). The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counselling, 26*(3), 257–269.

Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programs for parents of children with autism: Feasibility and preliminary outcome data. *Mindfulness, 4*(2), 89–101.

Gibaud-Wallston, J., & Wandersman, L. P. (1978). *Parenting sense of competence scale.* Lawrence Erlbaum Associates.

Gika, D. M., Artemiadis, A. K., Alexopoulos, E. C., Darviri, C., Papanikolaou, K., & Chrousos, G. P. (2012). Use of a relaxation technique by mothers of children with autism: A case-series study. *Psychological Reports, 111*(3), 797–804.

Grindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders, 39*(1), 42–56.

Hare, D. J., Pratt, C., Burton, M., Bromley, J., & Emerson, E. (2004). The health and social care needs of family carers supporting adults with autistic spectrum disorders. *Autism, 8*(4), 425–444.

Imms, C., Adair, B., Keen, D., Ullenhag, A., Rosenbaum, P., & Granlund, M. (2016). 'Participation': A systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Developmental Medicine and Child Neurology, 58*(1), 29–38.

Ji, B., Zhao, I., Turner, C., Sun, M., Yi, R., & Tang, S. (2014). Predictors of health-related quality of life in Chinese caregivers of children with autism spectrum disorders: A cross-sectional study. *Archives of Psychiatric Nursing, 28*(5), 327–332.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15*(3), 247–277.

Kaminski, J. W., Valle, L. A., Filene, J. H., & Boyle, C. L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology, 36*(4), 567–589.

Kielhofner, G. (Ed.). (2008). *Model of human occupation: Theory and application.* Lippincott Williams & Wilkins.

Kuhaneck, H. M., Madonna, S., Novak, A., & Pearson, E. (2015). Effectiveness of Interventions for Children With Autism Spectrum Disorder and Their Parents: A Systematic Review of Family Outcomes. *The American Journal of Occupational Therapy, 69*(5) pp. 6905180040p1-14.

Laugeson Elizabeth, A., Fred, F., Catherine, M., & Dillon Ashley, R. (2009). Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(4), 596–606.

Leadbitter, K., Aldred, C., McConachie, H., Le Couteur, A., Kapadia, D., Charman, T., ... PACT Consortium (2018). The autism family experience questionnaire (AFEQ): An ecologically-valid, parent-nominated measure of family experience, quality of life and prioritised outcomes for early intervention. *Journal of Autism and Developmental Disorders, 48*(4), 1052–1062.
Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P., ... Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: Explanation and elaboration. *PLoS Medicine, 6*(7), e1000100.
Lin, L., Chu, H., Murad, M. H., Hong, C., Qu, Z., Cole, S. R., ... Chen, Y. (2018). Empirical comparison of publication bias tests in meta-analysis. *Journal of General Internal Medicine, 33*(8), 1260–1267.
McConachie, H., Parr, J. R., Glod, M., Hanratty, J., Livingstone, N., Oono, I. P., ... Garland, D. (2015). *Systematic review of tools to measure outcomes for young children with autism spectrum disorder*.
Mcconachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. *Journal of Evaluation in Clinical Practice, 13*(1), 120–129.
MacKay, T., Knapp, M., Boyle, J., Iemmi, V., Connolly, M., & Rehill, A. (2018). *The Microsegmentation of the Autism Spectrum: Economic and research implications for Scotland.* The Scottish Government.
Matson, M. L., Mahan, S., & Matson, J. L. (2009). Parent training: A review of methods for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*(4), 868–875.
Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science, 6*(1), 1.
Montes, G., & Halterman, J. S. (2008a). Child care problems and employment among families with preschool-aged children with autism in the United States. *Pediatrics, 122*(1), e202–8.
Montes, G., & Halterman, J. S. (2008b). Association of childhood autism spectrum disorders and loss of family income. *Pediatrics, 121*(4) pp. e821–6.
National Research Council (2001). *Educating children with autism (Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education)*. Washington, DC: National Academy Press.
National Institute for Health and Clinical Excellence (NICE) (2012). *Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum [CG142].* London: National Institute for Health and Clinical Excellence; NICE 2012.
National Institute for Health and Clinical Excellence (NICE) (2011). *Autism: Recognition, referral and diagnosis of children and young people on the autism spectrum [CG128].* London: National Institute for Health and Clinical Excellence; NICE 2011.
National Institute for Health and Clinical Excellence (NICE) (2014). *A summary of selected new evidence relevant to NICE clinical guideline 142 'Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum' (2012).* London: National Institute for Health and Clinical Excellence; NICE 2014.
Nikmat, A. W., Ahmad, M., OON, N., & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal of Psychiatry, 9*(2), 65–72.
Ogletree, B. T., Oren, T., & Fischer, M. A. (2007). Examining effective intervention practices for communication impairment in autism spectrum disorder. *Exceptionality, 15*(4), 233–247.
Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *The Cochrane Database of Systematic Reviews,* (4), CD009774.
Patra, S., Arun, P., & Chavan, B. S. (2015). Impact of psychoeducation intervention module on parents of children with autism spectrum disorders: A preliminary study. *Journal of Neurosciences in Rural Practice, 6*(4), 529.
Pickles, A., Harris, V., Green, J., Aldred, C., McConachie, H., Slonims, V., ... Charman, T. (2015). Treatment mechanism in the MRC preschool autism communication trial: Implications for study design and parent-focussed therapy for children. *Journal of Child Psychology and Psychiatry, 56*(2), 162–170.
Roberts, D., & Pickering, N. (2010). Parent training programme for autism spectrum disorders: An evaluation. *Community Practitioner, 83*(10).
Rubin, E., Prizant, B. M., Laurent, A. C., & Wetherby, A. M. (2013). *Social communication, emotional regulation, and transactional support (SCERTS). Interventions for autism Spectrum disorders*. New York: Springer107–127.
Ruiz-Robledillo, N., Sariñana-González, P., Pérez-Blasco, J., González-Bono, E., & Moya-Albiol, L. (2015). A mindfulness-based program improves health in caregivers of people with autism spectrum disorder: A pilot study. *Mindfulness, 6*(4), 767–777.
Russa, M. B., Matthews, A. L., & Owen-Deschryver, J. (2015). Expanding supports to improve the lives of families of children with autism Spectrum disorder. *Journal of Positive Behavior Interventions, 17*(2), 95–104.
Samadi, S. A., McConkey, R., & Kelly, G. (2013). Enhancing parental wellbeing and coping through a family-centred short course for Iranian parents of children with an autism spectrum disorder. *Autism, 17*(1), 27–43.
Sanders, M. R., & Woolley, M. L. (2005). The relationship between maternal self-efficacy and parenting practices: Implications for parent training. *Child: Care, Health and Development, 31*(1), 65–73.
Singh, N. N., Lancioni, G. E., Winton, A. S., Karazsia, B. T., Myers, R. E., Latham, L. L., ... Singh, J. (2014). Mindfulness-based positive behavior support (MBPBS) for mothers of adolescents with autism spectrum disorder: Effects on adolescents' behavior and parental stress. *Mindfulness, 5*(6), 646–657.
Scottish Intercollegiate Guidelines Network (SIGN) (2016). *Assessment, Diagnosis and Interventions for autism spectrum disorders.* Edinburgh: SIGN145.
Shah, R., Kennedy, S., Clark, M. D., Bauer, S. C., & Schwartz, A. (2016). Primary care–based interventions to promote positive parenting behaviors: A meta-analysis. *Pediatrics, 137*(5), e20153393.
Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current Psychiatry Reports, 14*(6), 732–738.
Sofronoff, K., Leslie, A., & Brown, W. (2004). Parent management training and Asperger syndrome: A randomized controlled trial to evaluate a parent based intervention. *Autism, 8*(3), 301–317.
Solomon, M., Ono, M., Timmer, S., & Goodlin-Jones, B. (2008). The effectiveness of parent–child interaction therapy for families of children on the autism spectrum. *Journal of Autism and Developmental Disorders, 38*(9), 1767–1776.
Suppo, J., & Floyd, K. (2012). Parent training for families who have children with autism: A review of the literature. *Rural Special Education Quarterly, 31*(2), 12–26.
Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Curtis, J. (2015). A preliminary investigation into the effectiveness of a group-delivered sleep management intervention for parents of children with intellectual disabilities. *Journal of Intellectual Disabilities, 19*(4), 342–355.
Stuttard, L., Beresford, B., Clarke, S., Beecham, J., & Morris, A. (2016). An evaluation of the Cygnet parenting support programme for parents of children with autism spectrum conditions. *Research in Autism Spectrum Disorders, 23*, 166–178.
Tavernor, L., Barron, E., Rodgers, J., & McConachie, H. (2013). Finding out what matters: Validity of quality of life measurement in young people with ASD. *Child: Care, Health and Development, 39*(4), 592–601.
Tellegen, C. L., & Sanders, M. R. (2014). A randomized controlled trial evaluating a brief parenting program with children with autism spectrum disorders. *Journal of Consulting and Clinical Psychology, 82*(6), 1193.
Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. *Worldviews on Evidence-Based Nursing, 1*, 176–184. https://doi.org/10.1111/j.1524-475X.2004.04006.x.
Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E., ... Crabtree, E. (2010). Using group-based parent training interventions with parents of children with disabilities: A description of process, content and outcomes in clinical practice. *Child and Adolescent Mental Health, 15*(3), 171–175.
Van Heijst, B. F., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism, 19*(2), 158–167.
Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 23*, 36–49.
Watson, S. L., Hayes, S. A., Coons, K. D., & Radford-Paz, E. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: A qualitative comparison of parenting stress. *Journal of Intellectual & Developmental Disability, 38*(2), 105–113.

Weiss, J. A., Viecili, M. A., Sloman, L., & Lunsky, Y. (2013). Direct and indirect psychosocial outcomes for children with autism spectrum disorder and their parents following a parent-involved social skills group intervention. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 22*(4), 303.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009a). Do parental attributions affect treatment outcome in a parenting program? An exploration of the effects of parental attributions in an RCT of stepping Stones Triple P for the ASD population. *Research in Autism Spectrum Disorders, 3*, 129–144. https://doi.org/10.1016/j.rasd.2008.05.002.

Whittingham, K., Sofronoff, K., Sheffield, J., & Sanders, M. R. (2009b). Stepping Stones Triple P: An RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. *Journal of Abnormal Child Psychology, 37*, 469–480. https://doi.org/10.1007/s10802-008-9285-x.

Winner, M. G., & Crooke, P. J. (2009). Social Thinking: A developmental treatment approach for students with social learning/social pragmatic challenges. *Perspectives on Language Learning and Education, 16*(2), 62–69. https://doi.org/10.1044/lle16.2.62.

World Health Organization (2007). *The international classification of functioning, disability and health, children and youth version (ICF-CY)*. Geneva: WHO. http://www.who.int/classifications/icf/en/.